Adherence Behaviors in Youth Following the Completion of an Intensive Interdisciplinary Pain Rehabilitation Program

By

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Abstract

Chronic pain in youth is increasing and there is limited research regarding adherence behaviors in this population. As treatment is commonly an interdisciplinary approach involving a combination of medical, psychological, and physical treatments, it is important to understand how youth adhere to multiple treatment recommendations. Limited research suggests that adherence for youth with chronic pain is variable and often dependent on the type of recommendation. The current study evaluated adherence behaviors for youth following completion of an intensive interdisciplinary pain treatment (IIPT) program at one-month, six-month, and 12-month follow up appointments. Data collection included a retrospective medical record review of 122 patients with chronic pain who had completed the IIPT program. Results indicated variable levels of adherence for youth with highest rates occurring for recommendations related to exercise and counseling participation. Lowest adherence rates were reported for self-regulation recommendations. Overall adherence rates were found to be statistically different between one-month (M=6.23; SD=1.68) and six-month (M=5.21; SD=1.89) follow up appointments (p=0.001) with lower adherence at six-month follow up. Functional disability, quality of life, and pain intensity were not significantly correlated with adherence rates at any follow up appointments. Depression, anxiety, pain acceptance, pain interference, and insurance type were not found to predict adherence rates at one-month follow up appointments. This study provides initial information regarding adherence for youth following completion of an IIPT program as well as providing longitudinal adherence information over the first year following program completion. Continued research is needed in order to generalize findings. Formalized assessment of adherence should be incorporated in future research.

Keywords: adherence, chronic pain, pediatric

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Introduction

Chronic pain is described as pain that continues past the period of healing (usually over 3 months) along with low levels of identified pathology that are not an adequate explanation of the presence and extent of the pain (Jacobsen & Mariano, 2001). Additionally, it is defined as persistent pain that "disrupts sleep and normal living, ceases to serve a protective function, and instead degrades health and functional capability" (Chapman & Stillman, 1996, p. 315). Lifetime and point prevalence rates in children and adolescents range from 24% to 92%, respectively (van Gessel, BaBmann, & Kroner-Herwig, 2011). The prevalence of childhood chronic pain has increased over the last few decades (Bandell-Hoekstra et al., 2001; Sillanpaa & Anttila, 1996), however, rates can vary substantially depending on the study. In a systematic review of epidemiology studies, King and colleagues (2011) reported that chronic pain rates are generally higher in girls, increase with age, and are associated with lower socioeconomic status.

There are several diagnostic terms given for children with primary chronic pain presentations, such as Complex Regional Pain Syndrome (CRPS), Juvenile Fibromyalgia, Diffuse Idiopathic Pain, and Localized Idiopathic Pain (Hoffart & Wallace, 2014). The presentation of pain may vary across children with these conditions. Specifically, the pain may appear locally or widespread, it may have a rapid or gradual onset, and can be associated with swelling and changes in color or may be completely invisible (Hoffart & Wallace, 2014). Additionally, these children may experience substantial physical disability and challenges with school, peers, and family. An underlying aspect of these different conditions is a commonality of central and/or peripheral sensory amplification, and due to this common mechanism this group of pain syndromes have been given common diagnostic term, Amplified Pain Syndromes (APS; Hoffart & Wallace, 2014).

Psychosocial Impact of Chronic Pain

Chronic pain can have a major impact on a child's psychosocial functioning (van Gessel et al., 2011). Children who experience chronic pain are more likely to miss school (Chan, Piira, & Betts, 2005), not participate in social activities (Kashikar-Zuck, Goldschneider, Powers, Vaught, & Hershey, 2001), experience lower quality of life, and may develop internalizing symptoms in response to pain (van Gessel et al., 2011). Additionally, children and adolescents with unexplained chronic pain (UCP) commonly have a comorbid psychiatric diagnosis, predominantly anxiety disorders (Knook et al., 2011). Moreover, adolescents with chronic pain have an increased risk of suicidal ideation and attempts and this was true for both males and females (van Tilburg, Spence, Whitehead, Bangdiwala, & Goldston, 2011).

Public Health Significance of Chronic Pain

The economic impact of chronic pain in adolescents is high. A study in the U.K. found that the estimated yearly cost of treatment for chronic pain, both direct and indirect costs, to be £8,000 (approximately $16,000 USD) per child (Sleed, Eccleston, Beechma, Knapp, & Jordan, 2005). A recent study in the United States by Groenewald and colleagues (2014) reported that the annual costs to society are estimated to be $19.5 billion for youth with moderate to severe chronic pain. In a study investigating the healthcare utilization in a clinical chronic pain sample of adolescents compared to a community sample with intermittent pain complaints, the clinical sample had higher rates of healthcare utilization as well as higher medication use compared to the community sample. Additionally, authors reported that higher annual income, higher caregiver-reported activity limitations, and greater pain frequency were associated with a higher number of healthcare visits (Toliver-Sokol, Murray, Wilson, Lewandowski, & Palermo, 2010).

Chronic pain is also a problem that, if not treated effectively in childhood, will persist into adulthood. Knook and colleagues (2012) found that 75% of children and adolescents with chronic pain continued to experience chronic pain when assessed six years later. Several other studies have demonstrated that a considerable number of adolescents will have recurrent or persistent pain into adulthood (Brattberg, 2004; Clinch, & Eccleston, 2009; Fearon & Hotopf, 2001; Kashikar-Zuck et al, 2014; Walker, Dengler-Crish, Rippel, & Bruehl, 2010). Given that rates of chronic pain increase with age and chronic pain persists into adulthood (Knook et al., 2012), it is important to understand how children adhere to current treatments for chronic pain so it does not persist with advancing age. Thus, it is important to not only understand if treatment is effective, but how to help children be successful (e.g., adherent) with treatment. Research is limited in the area of adherence to treatments for children with chronic pain. Research does, however, exist regarding what factors play a role in children initiating treatment as well as factors that affect treatment success. There are some treatments for children with chronic pain that have demonstrated the possibility for remission or reductions of pain and functional limitations (Hoffart & Wallace, 2014).

Pediatric Chronic Pain Treatment

The approach to treatment for pediatric chronic pain varies depending on several factors, the type of pain problems, treatment provider, the hospital system, and what treatments are covered by insurers. The Biopsychosocial Model (Engel, 1980) emphasizes the interaction of the biomedical, psychological, social, and behavioral factors in understanding health, and is a widely accepted framework for understanding and treating chronic pain (Gatchel, Peng, Peters, Fuchs, & Turk, 2007). Multidisciplinary treatment for chronic pain typically consists of some combination of medical (e.g., medication, nerve blocks), physical (e.g., physical therapy (PT),

occupational therapy (OT), and psychological (e.g., cognitive behavioral therapy, biofeedback) treatments (Simons, Sieberg, Pielech, Conroy, & Logan, 2013).

Medication. Interestingly, research has demonstrated that medications have little efficacy in treating children with fibromyalgia, one of the most common amplified pain syndromes in children (Sherry et al., 2015), and reviews with adults are not promising (Moore, Derry, Aldington, Cole, & Wiffen, 2012; Moore, Straube, Wiffen, Derry, & McQuay, 2009; Uceyler, Hauser, & Sommer, 2008; Uceyler, Sommer, Walitt, & Hauser, 2013).

Interestingly, a population study found that 45.2% of visits for chronic pain were with primary care providers (PCPs) compared to 0.12% with a pain medicine specialist (Rasu, Sohraby, Cunningham, & Knell, 2013), indicating that education regarding chronic pain treatment may be important to implement at the level of family medicine and pediatrics so these children receive appropriate referrals.

Psychological. Evidence does not support standalone medical treatments for chronic pain; however, numerous systematic reviews and meta-analyses of randomized controlled trials of psychological interventions for children and adolescents have demonstrated that they can lead to reductions in pain frequency, severity, and duration and improve quality of life (Fisher et al., 2014; Eccleston, Morley, Williams, Yorke, & Mastroyannaopoulou, 2002; Palermo, Eccleston, Lewandowski, Williams, & Morley, 2010). There is strong evidence that psychological treatments, specifically involving relaxation and cognitive behavioral therapy, are effective in reducing both the frequency and severity of chronic pain in children and adolescents (Eccleston et al., 2002). One limitation of psychological interventions is that psychological therapies do not always target physical functioning (Palermo, 2009), a critical outcome variable for chronic pain patients. Researchers have noted that strict adherence to self-management strategies alone for

chronic pain may only account for a small amount of variance in outcomes in adults (Curran, de C Williams, & Potts, 2009). This is critical because not all chronic pain patients respond to typical pain management techniques, such as relaxation, distraction, and biofeedback training, (Weiss et al., 2013) and a treatment focused on increasing functioning may be necessary (Wicksell, Melin, Lekander, & Olsson, 2009). This is why the inclusion of a physical treatment (e.g., PT/OT) is important so that functioning is also a target of treatment.

Physical. The incorporation of exercise into treatment for APS is important (Gedalia et al., 2000). A study by Wilson and Palermo (2012) demonstrated, through the use of actigraphy, that children with chronic pain are less physically active when compared to healthy controls. It is uncommon for exercise to be delivered as a stand-alone treatment but it is an important component of an interdisciplinary approach to chronic pain (Hoffart & Wallace, 2014).

Outpatient Interdisciplinary Treatment vs Intensive Interdisciplinary Pain Treatment (IIPT). Psychological interventions that incorporate a treatment component that targets functioning are effective. Research has demonstrated that children with fibromyalgia can be treated successfully in an interdisciplinary program that incorporates intensive PT, OT and psychological therapies successfully and regain normal functioning, as well as achieve a reduction in pain and increased quality of life without the use of medications (Sherry et al., 2015). Interdisciplinary treatment programs for children and adolescents with chronic pain are growing and have led to reductions in disability, pain, and psychological distress (Hechler et al., 2009; Logan et al., 2012; Maynard, Amari, Wieczorek, Christensen, & Slifer, 2010). Intensive Interdisciplinary Pain Treatment (IIPT) programs frequently focus on encouraging patients to actively participate in the rehabilitation process and develop adaptive coping strategies for pain, such as acceptance, self-encouragement, minimizing pain, and distracting or ignoring pain

(Logan, Conroy, Sieberg, & Simons, 2012). Simons and colleagues (2013) reported positive improvements for patients in both a day hospital pain rehabilitation program and outpatient interdisciplinary pain treatment; however, patients participating in the intensive pain rehabilitation had significantly larger improvements in the areas of functional disability, pain-related fear, and readiness to change. Even with strong evidence supporting these intensive pain rehabilitation programs, there are still very few in the United States and there is scarce research on the long-term outcomes for the youth that participate in these programs (Simons et al., 2013).

Adherence to Treatment

Adherence to pediatric medical regimens is a challenge across chronic conditions, as children adhere to their prescribed regimens approximately 50% of the time (Rapoff, 2010). Pediatric pain populations present an additional challenge as treatment approaches frequently involve an interdisciplinary approach with multiple treatment modalities. There is limited research examining adherence to treatment in pediatric chronic pain populations and this research suggests that a significant proportion of children with chronic pain are not adherent to pain management recommendations (Simons, Logan, Chastain, & Cerullo, 2010). The following two sections briefly summarizes adherence in adult chronic pain as well as other pediatric chronic conditions that involve pain management, such as juvenile rheumatoid arthritis and sickle cell disease. This will be followed by a detailed discussion of the limited work in adherence for pediatric chronic pain.

Adherence and Chronic Pain in Adults. Research within adult chronic pain populations has assessed adherence to non-medical approaches more so than research with pediatric populations. In adults with chronic pain, poor adherence following a rehabilitative intervention has been linked to higher levels of distress (Jensen, Turner, & Romano, 1994) and fewer

treatment gains (Taimela, Diederich, Hubsch, & Heinricy, 2000). Higher levels of mood and self-efficacy in treatment have been shown to partially predict adherence levels to psychological treatment of adults with chronic pain (Curran et al., 2009). Nicholas and colleagues (2012) reported that adults who practiced at least four out of five of their prescribed pain self-management strategies consistently while in treatment experienced pain improvement, decreases in disability, and lower depression levels post-treatment. Authors also reported that outcomes were consistently worse with less practice of self-management strategies (Nicholas et al., 2012). In a study of women with fibromyalgia, low patient psychological distress and low patient-physician disagreement on patient well-being (e.g., disease activity, emotional well-being, and psychological distress) predicted higher adherence to treatment recommendations (Dobkin, Sita, & Sewitch, 2006). The association between high psychological distress and lower adherence rates is consistent in the literature on chronically ill adults (Dobkin et al., 2006). Additionally, motivational interviewing (MI) has been shown to increase adherence to treatment in the short-term in adults with chronic pain (Alperstein & Sharpe, 2016). Overall, the literature demonstrates that for adults, higher rates of adherence to pain management recommendations are associated with improvement in psychosocial outcomes.

Pediatric Adherence Research. Adherence is problematic in several chronic pediatric conditions where pain is a common symptom. Numerous adherence interventions have been created and implemented to improve adherence rates in children with chronic conditions; however, very little adherence intervention efforts have been targeted to pediatric chronic pain treatments. Three meta-analyses have been carried out in the last decade (Pai & McGrady, 2014; Graves, Roberts, Rapoff, & Boyer, 2010; Kahana, Drotar, & Frazier, 2008), and not one of these included a psychological adherence intervention for pediatric chronic pain; however, this is

expected, as little research exists on adherence rates in pediatric chronic pain. Other conditions with pain as a symptom, such as juvenile rheumatoid arthritis (JRA) and sickle cell disease (SCD), have been the focus of adherence. Higher self-esteem in patients with JRA has been associated with better adherence (Litt, Cuskey, & Rosenberg, 1982), suggesting that adding psychotherapy to boost self-esteem may be an important component of psychosocial treatments. In a study assessing barriers to adherence in pediatric patients with SCD, the authors reported that families had difficulty incorporating treatments into daily life, especially lifestyle changes (Modi, Crosby, Guilfoyle, Lemanek, Witherspoon, & Mitchell, 2009). Additionally, Modi and colleagues (2009) found that adolescents endorsed more barriers to pain management recommendations compared to their parents. More pain barriers were reported by parents of adolescents compared to younger children, suggesting pain management becomes more difficult during adolescence (Modi et al., 2009). Additionally, parents reported more barriers to following through with psychological treatment recommendations (MacNaughton & Rodrigue, 2001) than medical interventions for children referred for outpatient psychological services. Authors reported lower adherence to recommendations specific to psychological services compared to school-based recommendations and professional non-psychological consultation. MacNaughton and Rodrigue (2001) found that the number but not the type of barrier (such as access problems, financial problems, or negative beliefs) predicted adherence to psychological treatment recommendations. Due to the paucity of research in pediatric chronic pain, it will be important to first evaluate adherence rates and behaviors in this population so we can design ways to intervene with these children.

Adherence in Pediatric Chronic Pain. Simons and colleagues (2010) conducted the most extensive study on adherence to date for children and adolescents in an interdisciplinary

pain clinic. The study included 70 families that completed measures at an initial pain clinic evaluation and after three month follow up (Simons et al., 2010). Aims of this study included collecting data on adherence across different treatment recommendations, examining factors that influence engagement in self-management behaviors, and describing how engagement in treatment is associated with changes in functioning. Authors reported adherence to interdisciplinary treatment approaches ranged from 46.7% to 100% with the highest level of adherence to physical therapy recommendations (Simons et al., 2010). Different factors played a role in adherence outcomes depending on the type of treatment recommendation. Regarding adherence to physical therapy, the only positive association with adherence was familiarity with exercise (Simons et al., 2010). For the two-thirds of children and adolescents who were recommended psychological treatment, less than half followed these treatment recommendations (Simons et al., 2010).

Claar and Simons (2011) investigated adherence in children with chronic pain and their parents who went through a psychological intervention program. Similar to Simon and colleagues (2010), Claar and Simons (2011) found that approximately half of the patients followed through with recommendations specific to psychological treatment (e.g., cognitive-behavioral therapy). Patients were also provided with recommendations related to medication and physical therapy but adherence to these recommendations were not measured (Claar & Simons, 2011).

Research has suggested that the type of recommendation along with attitudes toward that recommendation influences adherence rates. Families looking for a medical solution to treatment may be more likely to follow medical recommendations compared to other recommendations, such as psychological or physical therapy (Simons et al., 2010). In a study of children with chronic pain, positive parental expectations regarding psychological treatment and biofeedback

were associated with engagement in psychological treatment (Simons et al., 2010). Tsao and colleagues (2005) found that children expected the benefit of complementary and alternative medical (CAM) treatments to be relatively small, and speculated that this may have resulted in lower adherence to CAM treatments (Tsao et al., 2005). Claar and Simons (2011) found that adolescents with chronic pain classified as "adaptive copers," (who utilized acceptance, self-encouragement, or social support seeking), reported higher expectations for the effectiveness of psychological treatment compared to "non-adaptive copers," suggesting that adaptive copers may be more receptive to psychological intervention for chronic pain and thus have higher levels of treatment participation. This also indicates that those classified as "nonadaptive copers" may need additional encouragement to participate in treatment (Claar & Simons, 2011).

Simons et al. (2010) assessed barriers to adherence for parents of youth with chronic pain. Parents identified several challenges and responses were categorized into four domains: (1) access problems, (2) financial problems, (3) competing time or schedule demands, and (4) negative beliefs (Simons et al., 2010). A barrier specific for adherence to medical recommendations was beliefs regarding that intervention; no barriers were associated with adherence to psychological and physical therapy recommendations. Simons and colleagues also evaluated the influence of satisfaction with the initial evaluation on treatment adherence. The authors reported that only adherence to medical recommendations was associated with satisfaction, specifically that parents of adolescents who were more satisfied had higher adherence to medical recommendations. However, the authors reported that the questions specific to satisfaction were more targeted toward the medical components (Simons et al., 2010). Also, patient satisfaction was not assessed in this study, only parent satisfaction. Two limitations of this study were that authors only asked about barriers if an individual was not 100% adherent

to that recommendation and they did not investigate the effect of quantity of barriers on patient and family participation in treatment (Simons et al., 2010).

In the adult literature, patient satisfaction is a factor that has been demonstrated to influence participation in treatment; however, there is contradictory evidence regarding the direction of this relationship between chronic pain and patient satisfaction. Chronicity of pain is typically associated with less satisfaction (Lehman & Zastowny, 1983; McNamee & Mendolia, 2014); however, there is research suggesting that some patients who experience little symptom relief can still be highly satisfied with treatment, specifically among the chronic pain population (Donovan, 1983; Ward & Gordon, 1996; Pellino & Ward, 1998; Hirsh et al., 2005). This may indicate that treatment satisfaction for chronic pain may depend more on additional variables other than symptom relief (Hirsh et al., 2005). In a study with adults with chronic pain, Hirsh and colleagues (2005) found that satisfaction was not achieved by solely reducing pain symptoms and that patients who thought their pain problem was explained well to them by their provider reported higher levels of satisfaction.

Simons and colleagues (2010) reported that engagement in psychological treatment was associated with decreases in functional limitations, lower rates of healthcare utilization, decreases in somatic symptoms, fewer school absences, and lower pain ratings. Interestingly, the authors reported that an increase in functional disability and pain ratings was associated with higher adherence to physical therapy recommendations (Simons et al., 2010). This negative association may have been due to adolescents still being engaged in physical therapy at follow up, which may increase their pain in the short-term but increase their functioning in the long-term. Another possibility is that these individuals may still be experiencing symptoms and would be more likely to report limitations (Simons et al., 2010).

The association between adherence to a prescribed regimen and reduction of symptoms has been given little attention in the literature. Nicholas and colleagues (2012) found that adherence to pain-management strategies was related to the improvement of psychological well-being during treatment; however, authors additionally reported that adherence to self-management strategies alone may not be sufficient to guarantee improvements in pain because other factors may also contribute to treatment changes, such as cognitive process variables (e.g., catastrophizing, fear-avoidance, and pain self-efficacy). Treatments for chronic pain are not perfect and thus full adherence by patients may not guarantee symptom relief (Turk & Rudy, 1991). Some pediatric research, outside of pediatric chronic pain, has suggested that adherence to treatment regimens may even negatively affect quality-of-life (Barakat, Lutz, Smith-Whitley, & Ohene-Frempong, 2005). If treatment recommendations are not leading to obvious improvements for patients, this may lead to a decrease in adherence as well as setbacks in provider-patient relationships.

Several research studies have investigated potential factors that could affect adherence rates in children and adolescents with chronic pain. However, few studies have investigated actual adherence or utilized the term adherence in research. There are several challenges to assessing adherence in pediatric chronic pain, which may be the reason there is a lack of research in the area. One challenge is that treatment is not standardized and varies depending on treatment site and the patient/family characteristics. The focus in the treatment of pediatric chronic pain has been on engagement in treatment or treatment initiation, not adherence. A lack of treatment initiation or engagement could also be conceptualized as a complete lack of adherence to what was recommended by the provider; however, this typically is not stated in the literature. Terms such as compliance, adherence, and engagement are often used interchangeably in the chronic

illness literature. However, each term has its own definition and there are slight differences between the terms. Other potential factors exist that may play a role in adherence rates and should be considered in future research in this area.

Potential Factors Affecting Adherence in Pediatric Chronic Pain

Research in the area of pediatric chronic pain is growing with several studies investigating factors that may influence outcomes of treatment. Even though these studies do not directly investigate the impact of adherence on treatment outcomes, the factors addressed could affect adherence and treatment outcomes. Factors that may play a role on adherence rates will be discussed along with incorporating theoretical perspectives.

Readiness to change. Guite and colleagues (2014) assert that readiness to change is an important part of understanding patient adherence to chronic pain treatment. An individual's level of readiness to adopt a self-management approach has been demonstrated to be an important factor for successful pain self-management in the adult literature (Logan et al., 2012), and increased readiness to change is associated with improvements in pain and psychological functioning after completion of an adult interdisciplinary pain treatment program (Jensen, Nielson, Turner, Romano, & Hill, 2003; Jensen, Nielson, Rutner, Romanao, & Hill, 2004; Kerns & Rosenberg, 2000).

The concept of readiness to change is associated with the Transtheoretical Model of Change (TTM; Prochaska & DiClemente, 1984). The TTM was originally applied to systems of psychotherapy and smoking cessation (Prochaska, 1979) and later extended to specific health behaviors, such as exercise, dieting, and diabetes care (Ruggiero, 2000). This model has two major dimensions: (1) stages of change and (2) processes of change. This can be viewed as the "when" and the "how" of participating in treatment (Rapoff, 2010). The progression through

these stages can vary and may include an individual skipping stages or regressing back to previous stages (Rapoff, 2010). Readiness to change could significantly impact adherence levels because one would assume a patient not ready to actively participate in treatment would not even be engaged. This may be a beneficial area to assess prior to engagement in interdisciplinary treatment as much of this treatment involves self-management that needs to be initiated by the patient. Techniques such as motivational interviewing can assist patients in advancing to the stage of active involvement in treatment.

Patient Beliefs. The Self Regulation Model (SRM) proposes that individuals' beliefs help them understand their symptoms and cope with health threats. The belief that treatment could control a person's illness has been connected to higher treatment adherence (Baines & Wittkowski, 2013). Beliefs about pain may play a role in a patient and family's initiation of and adherence to effective treatments for chronic pain (Guite et al., 2014). Research demonstrates that threatening beliefs regarding pain, such as pain catastrophizing, can influence the type of strategies utilized to cope with pain (Walker et al., 2005; Walker, 2008). One study found that lower pain catastrophizing was associated with greater readiness to change (Guite et al., 2014).

Individual differences. Demographic variables, such as race and socioeconomic status, have been investigated as predictors of adherence. Race emerged as a significant predictor of adherence in a sample of children referred for outpatient psychological treatment (MacNaughton & Rodrigue, 2001) However, this could be because minority populations have limited access to services and do not have providers who are both linguistically and ethnically matched (Sue, 1998; Wood, Hayward, Corey, Freeman, & Shapiro, 1990). Additionally, there are few psychologists who specialize in treating minority populations (Simons et al., 2010). An additional consideration is that minority populations may experience more treatment barriers and

not even make it for an initial evaluation in a pain clinic. This is an important area of research as higher rates of pediatric chronic pain are associated with lower socioeconomic status and minority status (King et al., 2011).

The influence of comorbid psychological diagnoses is an important factor that could play a role in treatment. In a study evaluating the effects of anxiety on cognitive behavioral therapy (CBT) for children with chronic pain, the authors speculated that children experiencing anxiety may be more likely to be adherent, although adherence to treatment recommendations from medical providers was not measured. However, those with anxiety were also less likely to improve following intervention compared to peers without anxiety (Cunningham et al., 2016). Additionally, depression is common in youth with chronic pain (Kashikar-Zuck et al., 2001) and related to lower adherence (Ciechanowski, Katon, & Russo, 2000; DiMatteo, Lepper, & Croghan, 2000; Grenard et al., 2011).

The Health Belief Model (HBM) was initially developed to understand why individuals fail to engage in preventive health services and was later expanded to adherence to prescribed medical regimens (Janz & Becker, 1984; Rosenstock, 1974). The Health Belief Model takes into account a person's beliefs about the recommended health behavior as an important determinant of performing that behavior (Jones et al., 2014). Expansions on the HBM have included self-efficacy (Strecher & Rosenstock, 1997), a concept from Bandura's Social Cognitive Theory (SCT; Bandura, 1986). SCT asserts that the probability a person will complete a health behavior is related to that person's beliefs that he or she has the knowledge and ability to perform that health behavior (e.g., self-efficacy) along with the belief that the health behavior will result in a beneficial outcome (Bandura, 1986). Adult and pediatric research has demonstrated that lower perceived self-efficacy negatively impacts self-care activities (Armstrong, Mackey, & Streisand,

2011; Easom, 2003). Jones and colleagues (2014) demonstrated that perceived severity and perceived barriers, as conceptualized in the HBM, negatively correlated with adherence in self-care behaviors in adolescents with food allergy. Specifically, youth reporting higher perceptions of severity had greater adherence and those that reported higher perceived barriers demonstrated a reduction in adherence behaviors (Jones et al., 2014).

The Children's Health Belief Model has been adapted from the HBM for pediatric populations (CHBM; Bush & Iannotti, 1990). This model includes similar dimensions of the original HBM while also incorporating caregiver roles and attitudes in a child's health behaviors (Rapoff, 2010). An application of the CHBM, or HBM, to pediatric chronic pain has not been carried out in research. A challenge of applying a theory related to medical adherence to pediatric chronic pain is that adherence theories are often focusing on a single health behavior. Treatment of chronic pain requires adherence to multiple treatment recommendations and a multitude of factors may play a role in a patient and family's decision to follow through with one treatment recommendation. Additionally, there has been some criticism of the HBM, specifically that there are several variations in the way constructs, such as barriers, are conceptualized and measured (Rapoff, 2010).

Summary. The potential factors discussed above need to be considered when evaluating adherence in pediatric chronic pain. It is important to discern whether these factors are associated with adherence and treatment outcomes for chronic pediatric pain. The relationship between adherence and treatment outcomes is important for researchers and clinicians to understand when working with children with chronic pain, as this will influence how they treat patients (i.e., addressing adherence or changing treatment recommendations). It may be beneficial for

researchers to incorporate traditional adherence theories when designing studies related to adherence in pediatric chronic pain as this is not currently done.

Study Aims and Hypotheses

Rehabilitation for Amplified Pain Syndromes (RAPS) is an intensive interdisciplinary program that treats children who are experiencing significant pain and disability who have not been successful in traditional outpatient treatment. The treatment program typically lasts between three and five weeks, dependent on the patient's unique needs as well as progress through treatment. One of the main goals of treatment is to restore normal physical function. Treatment activities include intensive physical and occupational therapy, stress-management training, relaxation techniques, individual and group therapy, music, and therapeutic art. All pain and sleep medications are discontinued prior to treatment.

All program participants leave the program with the same four treatment recommendations. Recommendations come from the core areas of treatment: Physical Therapy (PT), Occupational Therapy (OT), and Psychological Therapy. The recommendation from PT following completion of the program is to complete 45 minutes of aerobic exercise each day. This exercise should be completed even when youth are experiencing pain and the focus is on improvement in function (e.g., endurance, strength, speed). When the participant is no longer experiencing pain, the frequency of exercise may be decreased to four times a week. The recommendation from OT includes desensitization (e.g., rubbing, massaging, cold, heat) exercises 5 times a day for 5 to 10 minutes. Desensitization may discontinue if the participant is no longer experiencing allodynia (e.g., pain from touch). There are two recommendations specific to psychological treatment. The first includes participating in outpatient counseling biweekly at a minimum for at least four months. The second psychological recommendation is

for youth to participate in self-regulation exercises (e.g., deep breathing, imagery, progressive muscle relaxation, yoga, mindfulness) 2 to 3 times daily. All four of these recommendations are discussed at one-month, six-month, and 12-month follow up appointments after treatment completion.

Youth complete assessment measures related to psychosocial and health variables at multiple time points throughout the program as well as multiple follow-up appointments. Youth complete baseline measures on their first day of the program (which is on a Monday or Tuesday). While in the RAPS program, youth complete the same assessment packet at the end of every week that they are in the program (each Friday). Program completion always occurs on a Friday, which is the point at which youth complete their post-treatment assessment. Following completion of the program, youth attend follow-up appointments at one-month, six-months, and 12-months after treatment completion. Sometimes, youth attend additional follow-up appointments at three-months and nine-months post-treatment; however, these follow-up appointments do not include completing assessment measures and will not be utilized in this study.

This study examined adherence behaviors over time in youth following completion of the RAPS treatment program. Additionally, this study aimed to examine the relationship between adherence behaviors and health outcomes as well as identify potential predictors of adherence behaviors in youth with amplified pain syndromes. Through this study, the following hypotheses were tested:

Hypothesis 1 – Adherence Rates. I predict that adherence will decrease over time for youth following completion of the treatment program. Specifically, adherence rates will be higher at one-month follow up compared to 6-month and 12-month follow up. As the treatment

is highly structured, youth will experience difficulty incorporating multiple lifestyle behaviors into their daily routine and this will become more problematic the further out they are from treatment.

Hypothesis 2 – Adherence and Health. I predict that youth with lower rates of adherence will subsequently have worse ratings on health outcome measures (e.g., pain, QOL, disability) and this relationship will be true at all assessment points (e.g. one-month, six-months, 12-months since treatment completion).

Hypothesis 3 – Predictors of Adherence. I predict that youth with higher levels of reported anxiety, depression, and pain interference as well as lower scores of pain acceptance at the end of the RAPS program will be less adherent at one-month post-treatment assessment. Additionally, it is hypothesized that those who have public or no insurance will be less adherent at one-month follow-up.

Assessing adherence rates following completion of this treatment may provide additional target areas of treatment to improve long-term care of patients. Additionally, examining adherence rates over time may provide insight into reasons why these patients do, or do not, maintain treatment gains following completion of the RAPS program.

Methods

Participants

Data for the current study involved both a medical record review and REDCap data review of patients who had completed the RAPS program at Children's Mercy Hospital (CMH) in Kansas City, Missouri and were eligible to complete a one-month follow up appointment. Patients who did not complete the program were not included in this study due to not having any follow up adherence data available.

A power analysis was conducted to determine the necessary sample size to have adequate power in addressing study hypotheses, specifically hypothesis three regarding predictors of adherence. The G*Power 3.1.9.2 Program (Faul, Erdfelder, Lang, & Buchner, 2007) was utilized to estimate the sample size needed for a multiple regression equation (Faul, Erdfelder, Buchner, & Lang, 2009). Parameters input into the program included an effect size of f^2=0.15, which is considered a medium effect (Cohen, 1988); an alpha error probability of 0.05; power of 0.8, or 80%; and then the number of predictors tested in a linear multiple regression, which will include five predictors. The G* Power analysis reported a total sample size needed for a multiple regression analysis with the above parameters to be 92 participants.

Data Collection

All participants complete measures related to pain and psychosocial functioning on their first day of the treatment program, every week while in the program, at completion of the program and then again at three follow-up appointments after completion of the program (e.g., one-month follow-up, six-months follow-up, and 12-months follow-up). All measures, except adherence data, are collected through the use of Research Electronic Data Capture (REDCap) and are included in Appendix A. Adherence data and demographic information was recorded in the participant's medical record.

Measures

Medical Chart Review. Participant demographic information was abstracted from the medical record and REDCap. Information from the medical record included insurance type. Demographic information from REDCap included: age (at start of the RAPS program), gender, race/ethnicity, and length of time to complete RAPS program.

Functional Disability Inventory. The Functional Disability Inventory (FDI; Walker & Green, 1991) is a self-report measure with well-established psychometric properties (Claar & Walker, 2006) and clinical utility (Kashikar-Zuck et al., 2011) that is designed to assess disability in youth with chronic pain. It is a 15-item scale with a 5-point response scale (0=No Trouble; 1=A Little Trouble; 2=Some Trouble; 3=A Lot of Trouble; 4=Impossible) with scores ranging from 0 to 60. Higher scores indicated higher levels of perceived functional disability. Both child and parents versions of the measure were completed by participants.

Chronic Pain Acceptance Questionnaire. The Chronic Pain Acceptance Questionnaire, Adolescent version (CPAQ-A; McCracken, Gauntlett-Gilbert, & Eccleston, 2010) is a 20-item self-report measure of acceptance of chronic pain. It was adapted from the validated adult version (CPAQ; McCrackeen, Vowles, & Eccleston, 2004) and has demonstrated adequate internal consistency and validity as a measure of pain acceptance (Wallace, Harbeck-Weber, Whiteside, & Harrison, 2011). Item responses are on a 5-point scale (0=Never True; 1=Rarely True; 2=Sometimes True; 3=Often True; 4=Always True). Scores on the CPAQ-A range from 0 to 80 with higher scores indicating greater acceptance of pain.

PROMIS Measures. Four PROMIS (Patient Reported Outcome Measurement Information System; NIH) measures were utilized to evaluate areas of physical, psychological, and social functioning. The PROMIS measures included were Pain Interference, Anxiety, and Depression. All measures include eight items and ask participants to respond based on the past seven days on a 5-point scale (0=Never; 1=Almost Never; 2=Sometimes; 3=Often; 4=Almost Always). The Pain Interference Scale assesses the consequences of pain in areas of engagement such as social, cognitive, emotional, physical, and recreational activities. The Anxiety Scale assesses four symptom areas related to anxiety: fear, anxious misery, hyperarousal, and somatic

symptoms. The Depression Scale assesses four symptom areas related to depression: negative mood, views of self, social cognition, and decreased positive affect and engagement. All three of these scales have demonstrated adequate test-retest reliability and validity across groups (Varni et al., 2014).

Pediatric Quality of Life. The Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL™ 4.0; Varni, 1998) is a 23-item self-report measure of health-related quality of life. It includes four core scales: Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items), and School Functioning (5 items). Items are answered on a 5-point response scale (o=never a problem, 1=almost never a problem, 2=sometimes a problem, 3=often a problem, 4=almost always a problem). Items are reverse-scored and linearly transformed to a 0 to 100 scale (0=100, 1=75, 2=50, 3=25, 4=0) with higher scores indicating better HRQOL (Varni, Seid, & Kurtin, 2001). The PedsQL has demonstrated high reliability and validity while also being able to differentiate between healthy children and those with chronic illness (Varni et al., 2001).

Pain Locations. Participants reported on pain locations by selecting region(s) of the body where they experience pain. Participants select as many locations that apply to them from the following list of locations: (1) Head [not including face, jaw, or temple]; (2) Face, jaw, temple; (3) Throat, neck; (4) Shoulder; (5) Chest; (6) Upper Arm; (7) Elbow; (8) Forearm; (9) Wrist; (10) Hand; (11) Abdomen; (12) Hip; (13) Groin, pubic area; (14) Thigh; (15) Knee; (16) Calf; (17) Ankle; (18) Food; (19) Upper back; (20) Middle back; and (21) Lower back. A sum of the number of pain locations reported will be computed.

Pain Intensity. Participants reported on pain intensity by using a Visual Analog Scale (VAS) in REDCap where they indicate pain on a scale of 0 (no pain) to 100 (worst pain you can

imagine). Participants reported on their current pain level at time of completing assessment, average pain level over the last week, worst pain level in past week, and least pain level in last week. Additionally, participants reported how much their pain has affected them over the past week using a VAS with the 0 (no effect) to 100 (large effect) scale.

Adherence. Patient adherence information was collected at each follow-up visit following completion of the RAPS treatment program. Patients were asked by one of the team's medical providers, primarily the nurse practitioner or physician, whether they pursued each of the prescribed recommendations and the level at which they were completing that recommendation over the last 1-2 weeks. For each recommendation, patients were considered "fully adherent" if they completed the recommendation at 80% of the recommended "dose" or above of each recommendation. While there is no specified cut-off point for necessary adherence in chronic pain, this 80% is often referenced across chronic conditions and came from early studies on adherence to antihypertensive medications (Rapoff, 2010). Additionally, this is the clinical precedent in the RAPS program regarding what level of adherence to each recommendation would be expected to achieve clinical improvement. Details of what is considered 80% adherence for each treatment recommendation is discussed in more detail in the coding manual in Appendix B. Patients were considered "nonadherent" if they did not carry out a recommendation or participation was minimal and would not be expected to be associated with treatment gains. This cut-off point for nonadherent was discussed with a clinical provider, Dr. Dustin Wallace, who actively works with the RAPS group. The minimal level for each recommendation are as follows: exercising less than once a week on average; participating in desensitization less than an average of once a day; not participating in counseling or pursuing counseling services; and self-regulation exercises less than 3 times a week on average. More

details regarding the nonadherent category can be found in the coding manual in Appendix B. All participants who engaged in the treatment recommendation, but below the 80% cut-off point and above the minimal level for treatment gains were classified as "partially adherent." Similar to Simons et al. (2010), an adherence score will be calculated for each participant by totaling the ratings from each recommendation type ("fully adherent" = 2, "partially adherent" = 1, "nonadherent" = 0) at each post-treatment follow-up appointment. Please see coding manual in Appendix B for additional information on the coding process of adherence information.

Study Procedure

The CMH Institutional Review Board (IRB) approved this study protocol on November 16th, 2016. Only patients who had completed RAPS before this date were considered for inclusion in this study. Consent from participants was not required due to the nature of being a retrospective chart review.

Coding Procedures. I reviewed the medical charts of the patients who had completed the RAPS program at least one month prior to the IRB approval at CMH, which would indicate that the patient could have a one-month follow up appointment. I abstracted and coded relevant information related to adherence along with insurance provider information. To assess initial reliability of coding, a second rater (Stephanie Punt, MA) completed an independent review of the first 10% of adherence data utilizing the coding manual (Appendix B). The first 10% of coding was carried out to assess initial coding agreement to make determine if it was at an appropriate level. Discrepancies were discussed between raters before the final coding was completed. To assess interrater reliability with respect to the coding of adherence data, the same second rater independently coded a random 20% of the adherence data and the following statistical analysis was conducted. Cohen's kappa (Cohen, 1960) was calculated to examine

interrater reliability that required rater judgment in regards to applying adherence scores from information in medical notes. Cohen's kappa was 0.82, indicating acceptable interrater reliability. I resolved disagreements between raters through re-examination of the medical record.

Statistical Analyses

Data was extracted from the REDCap database and adherence data was entered to a Microsoft Excel Spreadsheet. All data were transferred to one data set and analyzed using IBM SPSS version 23 program. Preliminary analyses involved the use of descriptive statistics (means with standard deviations, medians, or percentages) to summarize the participant population on socio-demographic variables. Preliminary, descriptive analyses of individual variables were conducted first, followed by bivariate and multivariate analyses to test the study's hypotheses.

Results

Study Sample

At the time of IRB approval, 131 patients were in the RAPS data system who had enrolled in the program with time to also complete a one month follow up appointment. Nine patients were removed due to not completing the RAPS program.

The final sample, which included any patients that had any amount of adherence data, was 122 patients. The sample was predominantly female (84.4%) and, at the time of initiating the RAPS program, patients ranged in age from 10.0 years to 19.2 years (*M* (*SD*) = 15.3 (1.95) years). The majority of patients identified as White (90.2%) with 5.7% identifying as Black and 4.1% as Biracial. Eight patients identified as Hispanic. The majority of patients had a private insurance plan (78.7%). The remaining patients were on public insurance (18.9%) or self-pay (2.5%) for participation in the RAPS program.

Reported time with pain ranged from approximately eight months up to 15.5 years (*M* (*SD*) = 3.56 (3.67) years). Thirty-five patients reported full body pain (28.7%) and the most common location of pain reported was leg pain (64.8%) followed by back pain (43.4%). Program duration ranged from two to 11 weeks with most participants completing in three weeks (39.3%) or four weeks (41.8%).

Testing Hypothesis 1: Adherence Rates.

To assess adherence rates over time, descriptive analyses were carried out to provide data at each post-treatment assessment point (e.g., one-month, six-months, and 12-months post-treatment). Overall adherence rates were computed as well as adherence rates based on recommendation type. Additionally, to examine if changes in adherence from one-month follow-up to 12-month follow-up were significant, paired t-tests were conducted. Adherence to appointments were additionally evaluated for these participants and analyzed through the use of binomial tests. It should be noted that adherence does not reflect patients and their families calling the clinic and scheduling appointments, but rather the patients coming to appointments that were scheduled by a member of the RAPS team. The RAPS team reaches out to families to schedule appointments either while they are in clinic or over the phone.

One-Month Follow Up. One-month follow up appointments were scheduled for 122 patients and the attendance rate for this first follow up appointment was 91% (e.g. 11 cancelations or no shows). Of the 111 patients who completed the first follow up appoint at one-month post-treatment, 93 (83.8%) had adherence data information in the medical record relevant to each of the four treatment recommendations. Six patients were missing adherence data relevant to exercise (5.4%), 11 relevant to desensitization (9.9%), nine relevant to counseling (8.1%), and 14 relevant to self-regulation (12.6%).

Overall adherence rates were computed for patients with adherence data for each treatment recommendation (93 patients). Patients total adherence scores could range from 0-8 and the mean adherence score for the 93 patients was 6.23 (SD = 1.68). Twenty-five patients (26.9%) were fully adherent to treatment recommendations (e.g., received adherence scores of 8) and 22 patients (23.7%) received an adherence score of 7 indicating that half of the patients were fully or close to fully adherent at the first follow up appointment one-month post-treatment.

Six-Month Follow Up. Six-month follow up appointments were scheduled for 84 patients and the attendance rate for this follow up appointment was 85.7% (e.g., 12 cancelations or no shows). Of the 72 patients who completed the six-month follow-up appointment, 56 (77.8%) had adherence data recorded in the medical record relevant to each of the four treatment recommendations. Regarding missing adherence data information, four were missing data relevant to exercise (5.6%), eight relevant to desensitization (11.1%), five relevant to counseling (6.9%), and 12 relevant to self-regulation (16.7%).

Overall adherence rates were computed for the 56 patients with completed adherence data. The mean adherence score was 5.21 (SD=1.89). Adherence scores for this follow-up appointment ranged from 0-8. Six patients were fully adherent (10.7%) and eight patients (14.3%) received and adherence score of 7. This indicates that 25% of patients who attended the six-month follow up appointment were fully or close to fully adherent to all treatment recommendations. This is approximately half the proportion that were adherent (e.g., fully or close to fully adherent) at the one-month follow-up appointment.

Twelve-Month Follow Up. Twelve-month follow up appointments were scheduled for 59 patients and the attendance rate was 81.4% (e.g., 11 cancelations or no shows). Of the 48 patients who completed this follow up appointment, 39 (81.3 %) had adherence data relevant to

each treatment recommendation available in the medical record. One patient was missing data relevant to exercise (2%), three relevant to desensitization (6%), two relevant to counseling (4%), and five relevant to self-regulation (10%).

Overall adherence rates were computed for the 39 patients with completed adherence data and the mean score was 5.79 (SD=1.47). Adherence rates from this follow-up appointment ranged from 2-8; this was the only appointment where overall adherence scores of 0 and 1 did not occur. Five patients were fully adherence (12.8%) and eight patients (20.5%) received an adherence score of 7. This proportion of adherence scores is slightly higher compared to overall adherence scores at six-month follow-up and below the proportion of adherence rates at one-month follow up.

Adherence Rates Between Appointments. To examine if changes in adherence occur between follow up appointments, paired t-tests were conducted between all follow up appointments (see Figure 1). Differences in adherence rates were significant between one-month (M=6.23) follow up and six-month (M=5.21) follow up appointments (p=0.001). Differences in adherence rates were not significant between six-month (M=5.21) and 12-month (M=5.79) follow up appointments (p=0.062) or between one-month (M=6.23) and 12-month (M=5.79) follow up appointments (p=0.632).

Binomial tests were utilized to examine differences in rates of attendance between follow up appointments. The attendance rate was significantly different between one-month (91%) and 12-month (81.4%) follow up appointments (p=0.022). The attendance rate was not significantly different between one-month (91%) and six month (85.7%) follow up appointments (p=0.073) or six-month (85.7%) and 12-month (81.4%) follow up appointments (p=0.267).

Rates of Adherence Based on Recommendation Type. Rates of adherence based on recommendation are reported at each follow up visit and detailed in Table 1. Highest rates of adherence were reported for exercise (80.0%) and counseling (79.4%) at one-month follow up. Self-regulation, across all follow-ups, was consistently lower compared to other treatment recommendations.

Longitudinal Analysis of Adherence. To investigate what adherence over the first year post-RAPS completion, adherence rates were totaled and compared between patients who had full adherence data for all follow up appointments (n=23). Rates of adherence based on recommendation are reported at each follow up visit and detailed in Table 2. Overall adherence rates were computed for each follow up appointment and paired t-tests were conducted between all follow up appointments (see Figure 2). Differences in adherence rates were significant between one-month (M=6.26) follow up and six-month (M=5.48) follow up appointments (p=0.038). Differences in adherence were not significant between six-month (M=5.48) and 12-month (M=6.21) follow up appointments (p=0.115) or between one-month (M=6.26) and 12-month (M=6.21) follow up appointments (p=0.929)

Testing Hypothesis 2 – Adherence and Health.

To address the relationship between adherence rates and health outcomes, correlational analyses were utilized at each follow up assessment. Health variable means and standard deviations are included in Table 3 for one-month, six-month, and 12-month follow ups. Adherence rates did not correlate significantly with any of the included health outcome variables (e.g., pain intensity, quality of life, or disability) at one month follow up, six month follow up, or 12 month follow up. All correlations are listed in Table 4. Due to there being a different n for

each of the post-treatment assessment points, these correlations were not compared statistically over time.

Testing Hypothesis 3 – Predictors of Adherence.

Potential predictors of adherence at one-month follow up were examined through a stepwise multiple regression analysis. Predictors included depression, anxiety, pain acceptance, pain interference, and insurance type, assessed at RAPS completion, as predictors. Means and standard deviations of predictors are included in Table 3. Depression (β=0.16, *p*=.42), anxiety (β=0.02, *p*=.91), pain acceptance (β=0.13, *p*=.36), pain interference (β=-0.11, *p*=.50), and insurance type (β=0.12, *p*=.28), all assessed at RAPS completion, did not significantly predict adherence rates at one-month follow up.

Discussion

Understanding whether children and adolescents adhere to treatment recommendations and the factors that influence their adherence behavior is important (Simons et al., 2010). Interdisciplinary treatment programs for children and adolescents with chronic pain are growing and research is accumulating to provide outcome data of these programs. As interdisciplinary treatment programs are becoming more prevalent for children and adolescents with disabling chronic pain, it is important to understand how children and adolescents not only respond to treatment, but also how they fare post-treatment. This is the first known study to examine adherence behaviors following an Intensive Interdisciplinary Pain Treatment (IIPT) program. Gathering descriptive data proved to be challenging as well as demonstrated the need for more formalized assessment of adherence in this population with the use of psychometrically developed assessment measures.

An understanding of the long-term adherence in children with chronic pain is important because clinics are not often offering "cures," but rather encourage the long-term use of skills developed while attending pain clinics (Turk & Rudy, 1991). There is no available longitudinal research on long-term adherence in pediatric chronic pain. As symptoms of chronic pain typically persist past treatment, it is beneficial for children and their families to conceptualize treatment as more of a lifestyle change versus an acute treatment. This is the first study that provides data relevant to adherence over time following participation in an IIPT program. Results demonstrated that adherence rates are highest in the first month following program completion and then decrease following that appointment with the lowest adherence rates occurring at six-month follow up compared to 12-month follow up.

Generalization of treatment from the pain clinic to the home environment could prove difficult. Inpatient pain programs may not be conducive to patients adhering to recommendations post-treatment as these programs are often highly structured in a controlled environment which may not be available in natural settings (Turk & Rudy, 1991). The first aim of this study was to examine adherence rates over time as well as by recommendation type. With the exception of desensitization, rates of high adherence were lower across most recommendations at six-month follow up. As one-month follow up rates were generally higher, it indicates that youth were likely able to keep up the routine better in that first month and potentially struggled to keep up the rate of adherence over the next few months. This also could have been that youth were improving, related to health and functioning, which is a common reason that decreases in adherence are seen in youth. There are two potential considerations regarding the increase in adherence at the 12-month follow up appointment. On one hand, it would possibly indicate that youth noticed changes in pain over the time that adherence had decreased and saw the benefit of

resuming participation in treatment recommendations. However, another consideration is that the patients who followed up at 12-months were the more adherent patients in general (e.g., attending the year follow up) and thus more likely to have higher adherence races.

Exercise and counseling demonstrated higher overall rates of adherence compared to self-regulation and desensitization. Possibly these two were higher because participation in them is typically more structured (e.g., scheduled counseling sessions and scheduling when the 45 minutes of exercise will occur each day) and the frequency (e.g., times per day) of both is lower compared to desensitization and self-regulation, which occur multiple times each day. With regard to exercise, several of the youth who participate in the RAPS program have previously participated in physical therapy, potentially suggesting that it is easier to continue participation in an intervention that has previously been initiated (Simons et al., 2010).

The Simons et al. (2010) study found initiating a new psychological treatment to have the lowest rates of adherence with less than half of patients initiating those services. Adherence rates for participation in counseling were likely higher in this study for two potential reasons. The first being that a high number of individuals who participate in the RAPS program were participating in counseling prior to initiating the program; it is a recommendation made to all patients and families when they are evaluated by the RAPS team. A second potential reason is that all youth who participated in RAPS received psychological treatment throughout the program. This provided you with the opportunity to see benefits of that participation and those patients may be more likely to continue those services after completing the program. Exposure to counseling in RAPS may also address potential stigma or anxiety regarding meeting with a counselor.

Self-regulation demonstrated the lowest adherence rates compared to other treatment recommendations (e.g., exercise, desensitization, and counseling). The positive effects of self-

regulation may be too abstract for youth to see and thus their adherence is not as high compared to other recommendations where they may see more obvious benefits (e.g., increased endurance with increased exercise). Another potential challenge is that youth are encouraged to practice this skill, in the effort for mastery, outside of times they are feeling stressed or anxious. Youth likely notice the effects of self-regulation during moments of stress (e.g., diaphragmatic breathing to lower levels of anxiety), but they are instructed to practice these skills outside of stressful moments, which again may make it more difficult for youth to see benefit. While there were varying levels of adherence dependent on follow up appointment or type of recommendation, it should be noted that, overall, this sample demonstrated high adherence rates compared to overall adherence rates in pediatrics (e.g., 50%; Rapoff, 2010). While assessing participation in recommendations could have inflated these rates, they are still well above 50%, for certain recommendations.

The second aim of this study was to examine potential health factors that were related to adherence rates. Measurement method of adherence cannot be ignored as a potential issue due to the limited variability in adherence rates. It was assumed that a linear relationship between adherence and health outcomes would exist, as it is generally shown in regards to medical adherence that the higher the rate of adherence the better the health outcome. However, Table 2 demonstrates that the means across time points for health variables did not demonstrate high levels of variability. It is interesting to consider the potential of a curvilinear relationship between adherence and health outcomes in this population, which would likely lead to a low *r* (Goodwin & Leech, 2006). For example, it is possible that similar to adherence to medical regimens, that youth in this population who are not adherent to recommendations have lower health outcomes, it is also possible that youth in this population who are doing well, in regards to

health, discontinue certain aspects of treatment due to the positive changes in their health or choose not to continue participation after a certain period of time (e.g., following through with the recommended four months of counseling and stopping after that time period). While we would expect continuation in all treatment recommendations for this population as a positive approach to relapse prevention and continuation of improved health, it is possible that once youth in this population regain full functioning and have lower levels of pain that they do not need to continue with the prescribed treatment recommendations.

It is also possible that the adherence and health relationship does not exist in this group, specifically following such an intensive treatment that commonly leads to significant changes in health and disability prior to assessing adherence. Lastly, several of these patients do not end the program with a complete remission in pain symptoms and many leave with similar pain levels while there functioning has likely improved; thus, patients may be indicating high adherence while still endorsing frequent pain symptoms. Additionally, it may be that adherence to specific recommendations in this program and their relationship to health do not exist. More specifically, other intensive pain treatment programs utilize different "dosing" of recommendations (e.g., more focus on counseling compared to exercise).

The final aim of this study was to examine potential psychosocial predictors of adherence. Similar to the previous aim, measurement method cannot be ignored as a potential issue with this analysis. It is possible that adherence is not related to the included psychosocial variables, specifically after significant changes are observed during participation in RAPS. At the same time, there are other potential reasons why these factors that occur frequently in this population do not predict adherence. Rates of depression, anxiety, and pain interference were all low at RAPS completion (see Table 2). Similar to the discussion regarding the relationship

between adherence and health outcomes, one could potentially observe a curvilinear relationship between adherence and the included psychosocial variables. Some youth may have had higher adherence rates due to low levels of depression, anxiety, and pain interference and continued with this adherence because that is what they attributed the positive changes to regarding their mental and physical health. Other youth with low rates of the same variables may have discontinued treatment recommendations due to the improvements in both mental and physical health.

Limitations

Several limitations of this study were associated with the collection of adherence data. The retrospective review of the medical record, although with a formal coding method, still involved subjective decision-making regarding adherence score. There were instances where inferences regarding adherence rate were made through the coding process and these instances could have both over or underestimated actual adherence rates for youth. While adherence coding was completed by one individual (e.g., indicating some level of consistency related to interpretation of the medical record), adherence was recorded differently dependent on the provider who completed the follow up appointment note in the medical record. Additionally, as different providers gathered information relevant to adherence, it is possible the way patients were queried regarding participation in treatment recommendations elicited different responses from patients and their families. Research has demonstrated that nonjudgmental questions that are also specific and time-limited lead to more accurate reports of information as well as being less likely to elicit defensive responding (Rapoff, 2010). Lastly, attendance in counseling sessions was coded as fully adherent, but that does not necessarily reflect that youth are utilizing

skills suggested in counseling or even if they are discussing relevant topics during counseling sessions (e.g., the difficult topics).

Youth were queried regarding adherence to recommendations over the previous 1-2 weeks; however, it had been multiple weeks or months since youth were last evaluated on adherence. It is unclear if youth were providing an overall picture of adherence or if they were accurately representing their adherence in the recent weeks. It is possible patients and families were reporting overall adherence multiple weeks or months (e.g., more global estimate of adherence), compared to reporting on the previous 1-2 weeks. This may have been more likely if recent adherence had decreased. This could lead to potential overestimations or underestimations of adherence.

The categorical nature of the coding process limited the variability in adherence that could be observed in this population. More specifically, the catchment area of "partially adherent" is observing youth with, supposedly, adherence rates between 20 and 80 percent. Those are two different levels of participation in recommendations that, with more standardized measurement methods, could provide more detailed information about the differences between youths who fall in that catchment area.

The retrospective data review of the medical record did not allow for the opportunity to recover missing data. Specifically, if adherence information was missing for one or multiple treatment recommendations, there was not an opportunity to follow up with patients to gather that information. As there were enough youth with full adherence data at one-month follow up for adequate power, multiple imputation was not carried out as this may have overestimated or underestimated adherence rates in a population where little to no information regarding adherence information exists for comparison.

The study sample, which is similar to most studies of children with chronic pain, was predominantly female, white, and from the middle to upper socioeconomic class. The homogenous sample in this study limits generalizability to males and as well as ethnically and economically diverse children with chronic pain; however, it does represent the common demographics of youth with chronic pain (Gauntlett-Gilbert & Eccleston, 2007; Guite et al., 2007).

Other limitations of this study were the sample size in general, but more specifically at six-month and 12-month follow ups. Additionally, this study did not investigate any potential social variables that could contribute to adherence participation (e.g., access to a gym, counselor close to home, ability to travel to and from appointments). Finally, as this was the first study to examine adherence rates as well as how those adherence rates related to certain health and psychosocial variables, generalizability is limited due to the small and specific sample that was utilized in this study.

Future Directions

It would be interesting in future studies with larger samples to examine which treatment recommendation has the most significant effect, if at all, compared to the others. This would provide clinicians with beneficial information regarding which treatment recommendation may require more planning with a family in an effort for long-term prevention or relapse. There is no specific research regarding how much of each treatment (e.g., the dosing) is necessary for children to achieve symptom relief and the dosing of treatments will likely vary between pain clinics. All treatment recommendations in this study were considered lifestyle recommendations, compared to medication adherence. This is an area that is generally understudied compared to medication adherence, likely because of the difficulty in formally assessing this type of

adherence. At the same time, this is an important area to assess as these are common recommendations in psychological treatment.

There is also no adherence measurement method available for pediatric chronic pain outside of self-report, parent report, or provider report. This is a challenge in pediatric adherence research in general as self-report methods often overestimate adherence rates (Rapoff, 2010). Development of a more standardized measurement method would allow researchers and clinicians to observe more variance in adherence in this population. There are several considerations to take into account when evaluating adherence with children coping with chronic pain. One consideration is that adherence may look different between treatment clinics. If recommendations are not consistent between patients then adherence rates will likely vary more and will not be comparable between patients.

A better understanding of adherence in this population may give providers information about how to better target this behavior. Knowledge of adherence levels can additionally help inform providers about the effectiveness of treatment recommendations. Providers need to be able to differentiate between a lack of adherence and a treatment regimen that is not beneficial. If a patient is adherent to a treatment recommendation but is not experiencing any positive outcomes related to their overall health (both physical and/or psychological), then adherence will likely drop and this could create a blaming scenario between the patient and the provider.

There are other factors that were not explored as potential predictors of adherence in this study. Specifically, readiness to change (Guite et al., 2014), patient beliefs (Baines & Wittkowski, 2013; Guite et al., 2014), and comorbid psychological diagnoses. Additionally, the influence of parents was not assessed or utilized in this study. Other pediatric populations demonstrate that parents have a positive, significant impact on adherence, especially in

adolescence (King et al., 2014). Other studies within pediatrics indicate that decision-making competence in the adolescent is related to adherence (Miller & Drotar, 2007). As parents have the potential to have large impacts on adherence, both by either being more involved and increasing adherence or taking a step back as highly-involved parents and allowing children to not have perfect adherence. Assessing parents involvement in adherence would be especially interesting in this clinical population as parents are often encouraged to not ask about pain symptoms and to limit the amount of checking in they do with their children. Parent ratings of health may also reflect a different perspective on health (e.g., parents may view functioning and quality of life differently than youth). This would be an important area to assess in future studies.

Predictors utilized in regression analyses were assessed at RAPS completion; it would interesting to utilize baseline ratings of included predictors (e.g., anxiety, depression, pain acceptance, and pain interference) assessed prior to initiation the RAPS program. It is possible that youth demonstrate improvements in certain psychosocial variables (e.g., depression, anxiety, or pain interference) during RAPS participation and it may provide a better understanding of adherence to see where patients are with these variables prior to RAPS participation.

Due to the complexity of chronic pain, treatment often needs to be individualized. This further adds a layer of complexity when studying the variability of treatments and adherence in chronic pain (Broekmans, Dobbels, Milisen, Morlion, & Vanderschueren, 2009). The use of intensive physical and psychosocial treatment programs for pain conditions are becoming more prevalent and leading to positive outcomes for pediatric chronic pain patients. In a study of juvenile fibromyalgia, children who participated in an intensive program that included PT, OT, and psychological services exhibited improvement in nearly all of the functional and pain

measures, and these outcomes remained stable for a year after program completion (Sherry et al., 2015).

Overall, treatment for pediatric chronic pain is complex. The most successful treatments in improving overall function, pain severity, and psychological functioning in pediatric chronic pain involve participation in an interdisciplinary treatment approach. Measuring and studying adherence in this population is not a simple task, and this is not due to solely the complexity of treatment. This is also a complex population. There are several factors that can play a role in a patient's initiation and follow through with treatment recommendations and this study provides initial information regarding patient's engagement in treatment recommendations following an IIPT program. The prevalence of chronic pain continues to increase, and it is essential to continue to investigate how patients navigate through treatment and if they adhere to recommendations sufficiently to experience positive treatment outcomes.

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Table 1

Adherence to Recommendation Type at Each Follow Up Assessment

Recommendation	Fully Adherent % (n)	Partially Adherent % (n)	Not Adherent % (n)
Exercise			
1 month follow up (n=105)	80.0% (84)	15.2% (16)	4.8% (5)
6 month follow up (n=68)	51.5% (35)	33.8% (23)	14.7% (10)
12 month follow up (n=50)	64.0% (32)	26.0% (13)	10.0% (5)
Desensitization			
1 month follow up (n=100)	64.0% (64)	23.0% (23)	13.0% (13)
6 month follow up (n=64)	67.2% (43)	21.9% (14)	10.9% (7)
12 month follow up (n=48)	79.2% (38)	12.5% (n=6)	8.3% (4)
Counseling			
1 month follow up (n=102)	79.4% (81)	10.8% (11)	9.8% (10)
6 month follow up (n=67)	68.7% (n=46)	3.0% (2)	28.4% (19)
12 month follow up (n=49)	73.5% (n=36)	10.2% (n=5)	16.3% (n=8)
Self-Regulation			
1 month follow up (n=97)	43.3% (42)	32.0% (31)	24.7% (24)
6 month follow up (n=60)	23.3% (n=14)	35.0% (21)	41.7% (n=25)
12 month follow up (n=46)	32.6% (n=15)	34.8% (n=16)	32.6% (n=15)

Table 2

Adherence To Recommendation Type – Longitudinal Sample

Recommendation	Fully Adherent % (n)	Partially Adherent % (n)	Not Adherent % (n)
Exercise			
1 month follow up (n=23)	78.3% (18)	17.4% (4)	4.3% (1)
6 month follow up (n=23)	47.8% (11)	43.5% (10)	8.7% (2)
12 month follow up (n=23)	73.9% (17)	17.4% (4)	8.7% (2)
Desensitization			
1 month follow up (n=23)	56.5% (13)	26.1% (6)	17.4% (4)
6 month follow up (n=23)	73.9% (17)	17.4% (4)	8.7% (2)
12 month follow up (n=23)	69.6% (16)	17.4% (4)	13.0% (3)
Counseling			
1 month follow up (n=23)	82.6% (19)	17.4% (4)	0% (0)
6 month follow up (n=23)	82.6% (19)	0% (0)	17.4% (4)
12 month follow up (n=23)	91.3% (21)	4.3% (1)	4.3% (1)
Self-Regulation			
1 month follow up (n=23)	52.2% (12)	26.1% (6)	21.7% (5)
6 month follow up (n=23)	30.4% (7)	17.4% (4)	52.2% (12)
12 month follow up (n=23)	43.5% (10)	26.1% (6)	30.4% (7)

Table 3

Health and Psychological Variables Means and Standard Deviations

Variable	RAPS Completion	1 month	6 month	12 month
Pain Intensity	--	33.71 (30.51)	30.62 (30.41)	23.60 (31.34)
Functional Disability	--	7.08 (7.31)	6.08 (6.62)	6.02 (8.38)
QOL Activity	--	78.66 (17.18)	79.60 (18.78)	80.18 (20.40)
QOL Feeling	--	76.21 (22.45)	77.00 (22.43)	77.27 (22.45)
QOL Peers	--	83.84 (16.93)	86.43 (13.22)	86.71 (15.09)
QOL School	--	75.27 (19.54)	75.50 (18.04)	77.95 (19.81)
Depression	7.80 (8.17)	--	--	--
Anxiety	9.99 (8.54)	--	--	--
Pain Acceptance	50.53 (13.42)	--	--	--
Pain Interference	12.07 (8.28)	--	--	--

Table 4

Correlations between Adherence and Health Outcome Variables

1-Month Follow Up	Pain Intensity	Disability	QOL_Act	QOL_Feel	QOL_Peer	QOL_School
Total Adherence	0.05	0.11	0.03	-0.04	0.18	0.11
6-Month Follow Up	**Pain Intensity**	**Disability**	**QOL_Act**	**QOL_Feel**	**QOL_Peer**	**QOL_School**
Total Adherence	0.03	0.06	0.07	0.10	-0.04	-0.05
12-Month Follow Up	**Pain Intensity**	**Disability**	**QOL_Act**	**QOL_Feel**	**QOL_Peer**	**QOL_School**
Total Adherence	0.23	0.19	-0.25	-0.08	-0.10	-0.04

Figure 1.
Adherence Across Follow Ups

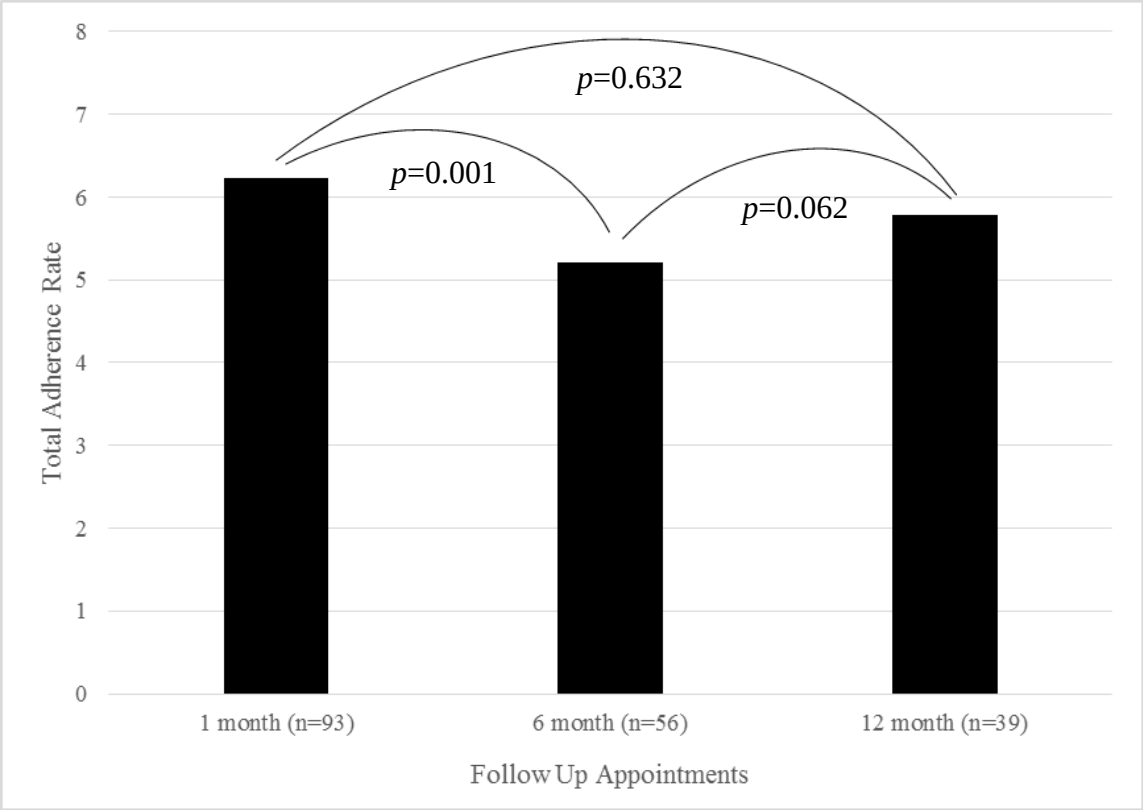
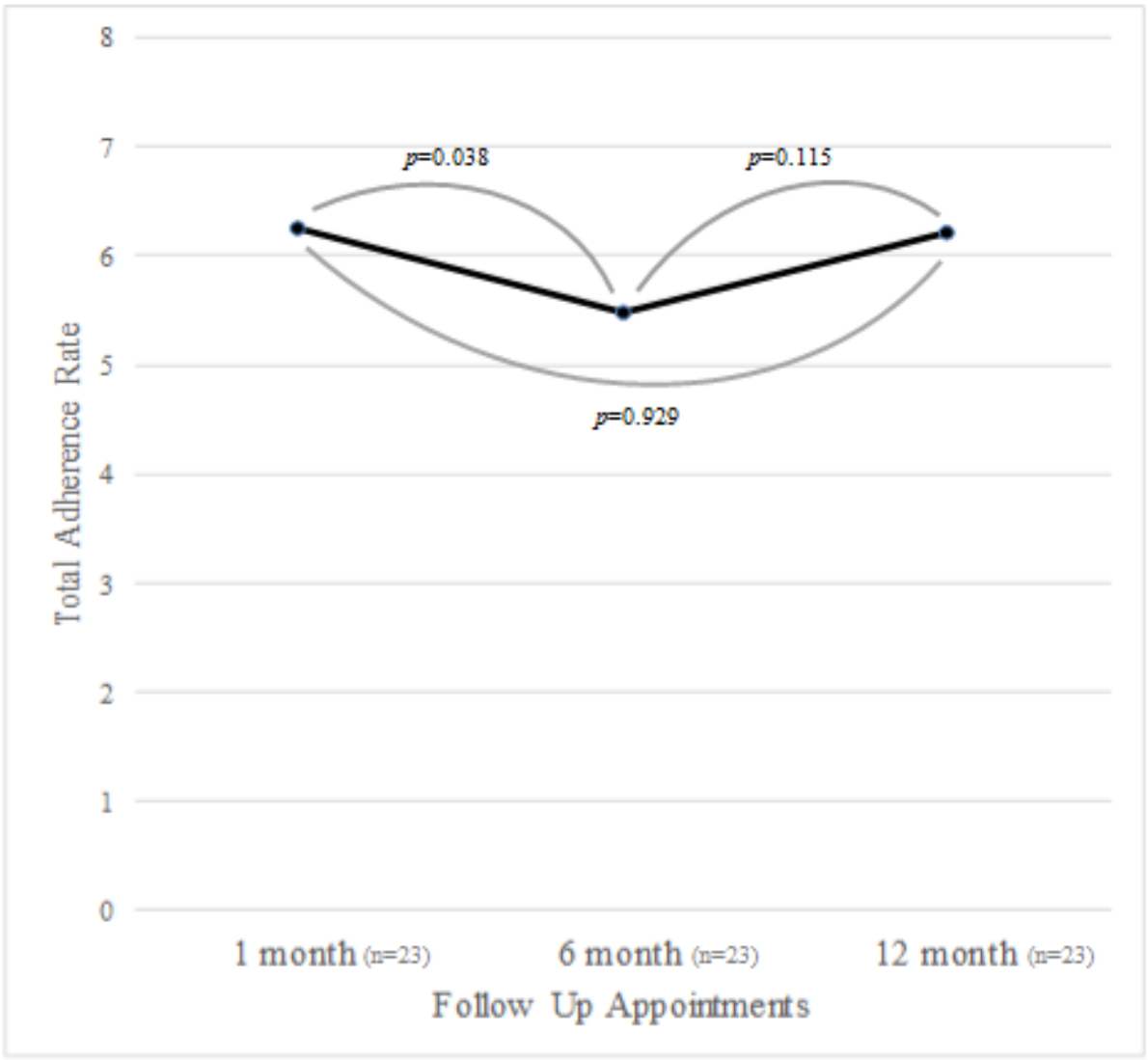


Figure 2
Adherence Across Follow Ups – Longitudinal Sample



Appendix A – REDCap Measures Packet

Confidential

Integrative Pain Management Clinic | Follow Up | Patient Forms

Please complete the forms below. Read each item carefully and answer to your best knowledge. Do not spend too much time on any one question. It is important that you answer all the questions. You may save your responses and return to the forms at a later time if necessary.

Thank you.

Integrative Pain Management | Patient Forms

How old are you?

_____
(What is your age in years?)

Use the slider to rate your AVERAGE energy level during the past WEEK.

0 — 100

(Place a mark on the scale above)

How much pain do you have NOW?

No Pain — Worst pain you can imagine

(Place a mark on the scale above)

Over the past WEEK, what was your WORST pain?

No Pain — Worst pain you can imagine

(Place a mark on the scale above)

Over the past WEEK, what was your LEAST pain?

No Pain — Worst pain you can imagine

(Place a mark on the scale above)

Over the past WEEK, what was your AVERAGE pain?

No Pain — Worst pain you can imagine

(Place a mark on the scale above)

Over the past WEEK, on AVERAGE, how much has pain affected your daily life?

No Effect — Large Effect

(Place a mark on the scale above)

Please indicate where you have had pain during the past WEEK.

Check all that apply.

- ☐ Head (NOT including your Face, Jaw, or Temple)
- ☐ Face, Jaw, Temple
- ☐ Throat, Neck
- ☐ Shoulder
- ☐ Chest
- ☐ Upper Arm
- ☐ Elbow
- ☐ Forearm
- ☐ Wrist
- ☐ Hand
- ☐ Abdomen
- ☐ Hip
- ☐ Groin, Pubic Area
- ☐ Thigh
- ☐ Knee
- ☐ Calf
- ☐ Ankle
- ☐ Foot
- ☐ Upper Back
- ☐ Middle Back
- ☐ Lower Back

Please specify the location of your pain.

During the past WEEK, I have had pain in the following locations on my FRONT SIDE:

	FRONT LEFT SIDE	FRONT RIGHT SIDE
Head (NOT including your Face, Jaw, or Temple)	☐	☐
Face, Jaw, Temple	☐	☐
Throat	☐	☐
Shoulder	☐	☐
Chest	☐	☐
Upper Arm	☐	☐
Elbow	☐	☐
Forearm	☐	☐
Wrist	☐	☐
Hand	☐	☐
Abdomen	☐	☐
Hip	☐	☐
Groin, Pubic Area	☐	☐
Thigh	☐	☐
Knee	☐	☐
Calf	☐	☐
Ankle	☐	☐
Foot	☐	☐

During the past WEEK, I have had pain in the following locations on my BACK SIDE:

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	BACK LEFT SIDE	BACK RIGHT SIDE
Head	☐	☐
Neck	☐	☐
Shoulder	☐	☐
Upper Arm	☐	☐
Elbow	☐	☐
Forearm	☐	☐
Wrist	☐	☐
Hand	☐	☐
Upper Back	☐	☐
Middle Back	☐	☐
Lower Back	☐	☐
Hip	☐	☐
Thigh	☐	☐
Knee	☐	☐
Calf	☐	☐
Ankle	☐	☐
Foot	☐	☐

Do you have headache pain?

◯ Yes ◯ No

PedsMIDAS_____DIRECTIONS The following questions try to assess how much the headaches are affecting day-to-day activity. Your answers should be based on the last month. There are no "right" or "wrong" answers so please put down your best guess.

1. How many full school days of school were missed in the last month due to headaches? _____

2. How many partial days of school were missed in the last month due to headaches (do not include full days counted in the first question)? _____

3. How many days in the last month did you function at less than half your ability in school because of a headache (do not include days counted in the first two questions)? _____

4. How many days were you not able to do things at home (i.e., chores, homework, etc.) due to a headache? _____

5. How many days did you not participate in other activities due to headaches (i.e., play, go out, sports, etc.)? _____

6. How many days did you participate in these activities, but functioned at less than half your ability (do not include days counted in the 5th question)? _____

CPAQ-A

DIRECTIONS Below you will find a list of statements. Rate how true each statement is as a statement about you.

	Never True (0)	Rarely True (1)	Sometimes True (2)	Often True (3)	Always True (4)
I am getting on with my life no matter what my level of pain is	○	○	○	○	○
My life is going well, even though I have chronic pain	○	○	○	○	○
It's O.K. to experience pain	○	○	○	○	○
I would give up important things in my life to control this pain better	○	○	○	○	○
I can do activities well even if I do not control my pain	○	○	○	○	○
I am living a normal life with my chronic pain	○	○	○	○	○
I need to concentrate on getting rid of my pain	○	○	○	○	○
I carry on with my normal activities when I feel pain	○	○	○	○	○
I do things that are important and things that are fun even though I have chronic pain	○	○	○	○	○
Controlling pain is less important than other goals in my life	○	○	○	○	○

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	Never True (0)	Rarely True (1)	Sometimes True (2)	Often True (3)	Always True (4)
My thoughts and feelings about pain must change before I can do things that are important to me	○	○	○	○	○
Despite the pain, I am staying on a particular course in my life	○	○	○	○	○
Keeping my pain under control is the most important thing whenever I am doing something	○	○	○	○	○
Before I can make any real plans, I have to get some control over my pain	○	○	○	○	○
When my pain increases, I can still do things I have to do	○	○	○	○	○
I will have better control over my life if I can control my thoughts about pain	○	○	○	○	○
I avoid situations where pain might increase	○	○	○	○	○
My worries and fears about my pain are true	○	○	○	○	○
I realize that I don't have to change my pain to get on with my life	○	○	○	○	○
I have to struggle to do things when I have pain	○	○	○	○	○

FDI - What you can do

When people are sick or having pain, it is sometimes difficult for them to do their regular activities. In the last few days, would you have had any physical trouble or difficulty doing these activities?

	No Trouble (0)	A Little Trouble (1)	Some Trouble (2)	A Lot of Trouble (3)	Impossible (4)
Walking to the bathroom	○	○	○	○	○
Walking up stairs	○	○	○	○	○
Doing something with a friend (for example playing a game)	○	○	○	○	○
Doing chores at home	○	○	○	○	○
Eating regular meals	○	○	○	○	○
Being up all day without a nap or rest	○	○	○	○	○
Riding the school bus or traveling in the car	○	○	○	○	○

Remember, you are being asked about difficulty due to physical health.

	No Trouble (0)	A Little Trouble (1)	Some Trouble (2)	A Lot of Trouble (3)	Impossible (4)
Being at school all day	○	○	○	○	○
Doing the activities in gym class (or playing sports)	○	○	○	○	○
Reading or doing homework	○	○	○	○	○
Watching TV	○	○	○	○	○
Walking the length of a football field	○	○	○	○	○
Running the length of a football field	○	○	○	○	○
Going shopping	○	○	○	○	○
Getting to sleep at night and staying asleep	○	○	○	○	○

PROMIS

Please respond to each item by marking one box per row. In the past 7 days...

	Never (0)	Almost Never (1)	Sometimes (2)	Often (3)	Almost Always (4)
I felt nervous.	○	○	○	○	○
I felt scared.	○	○	○	○	○
I felt worried.	○	○	○	○	○
I felt like something awful might happen.	○	○	○	○	○
I thought about scary things.	○	○	○	○	○
I was afraid that I would make mistakes.	○	○	○	○	○
I worried about what could happen to me.	○	○	○	○	○
I worried when I went to bed at night.	○	○	○	○	○

PROMIS

Please respond to each item by marking one box per row. In the past 7 days...

	Never (0)	Almost Never (1)	Sometimes (2)	Often (3)	Almost Always (4)
I had trouble sleeping when I had pain.	○	○	○	○	○
I felt angry when I had pain.	○	○	○	○	○
I had trouble doing schoolwork when I had pain.	○	○	○	○	○
It was hard for me to pay attention when I had pain.	○	○	○	○	○
It was hard for me to run when I had pain.	○	○	○	○	○
It was hard for me to walk one block when I had pain.	○	○	○	○	○
It was hard to have fun when I had pain.	○	○	○	○	○
It was hard to stay standing when I had pain.	○	○	○	○	○

PROMIS

Please respond to each item by marking one box per row. In the past 7 days...

	Never (0)	Almost Never (1)	Sometimes (2)	Often (3)	Almost Always (4)
I could not stop feeling sad.	○	○	○	○	○
I felt alone.	○	○	○	○	○
I felt everything in my life went wrong.	○	○	○	○	○
I felt like I couldn't do anything right.	○	○	○	○	○
I felt lonely.	○	○	○	○	○
I felt sad.	○	○	○	○	○
I felt unhappy.	○	○	○	○	○
I thought that my life was bad.	○	○	○	○	○

PedsQL (TM) - Pediatric Quality of Life Inventory (Version 4.0)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you during the past ONE month by circling: 0 if it is never a problem 1 if it is almost never a problem 2 if it is sometimes a problem 3 if it is often a problem 4 if it is almost always a problem There are no right or wrong answers. If you do not understand a question, please ask for help.

ABOUT MY HEALTH AND ACTIVITIES (problems with...)

	Never (0)	Almost Never (1)	Sometimes (2)	Often (3)	Almost Always (4)
1. It is hard for me to walk more than one block	○	○	○	○	○
2. It is hard for me to run	○	○	○	○	○
3. It is hard for me to do sports activity or exercise	○	○	○	○	○
4. It is hard for me to lift something heavy	○	○	○	○	○
5. It is hard for me to take a bath or shower by myself	○	○	○	○	○
6. It is hard for me to do chores around the hosue	○	○	○	○	○
7. I hurt or ache	○	○	○	○	○
8. I have low energy	○	○	○	○	○

ABOUT MY FEELINGS (problems with...)

	Never (0)	Almost Never (1)	Sometimes (2)	Often (3)	Almost Always (4)
1. I feel afraid or scared	○	○	○	○	○
2. I feel sad or blue	○	○	○	○	○
3. I feel angry	○	○	○	○	○
4. I have trouble sleeping	○	○	○	○	○
5. I worry about what will happen to me	○	○	○	○	○

HOW I GET ALONG WITH OTHERS (problems with...)

	Never (0)	Almost Never (1)	Sometimes (2)	Often (3)	Almost Always (4)
1. I have trouble getting along with other kids	○	○	○	○	○
2. Other kids do not want to be my friend	○	○	○	○	○
3. Other kids tease me	○	○	○	○	○
4. I cannot do things that other kids my age can do	○	○	○	○	○
5. Its hard to keep up when I play with other kids	○	○	○	○	○
1. I have trouble getting along with other teens	○	○	○	○	○
2. Other teens do not want to be my friend	○	○	○	○	○
3. Other teens tease me	○	○	○	○	○
4. I cannot do things that other teens my age can do	○	○	○	○	○
5. Its hard to keep up with my peers	○	○	○	○	○

ABOUT SCHOOL (problems with...)

	Never (0)	Almost Never (1)	Sometimes (2)	Often (3)	Almost Always (4)
1. It is hard to pay attention in class	○	○	○	○	●
2. I forget things	○	○	○	○	○
3. I have trouble keeping up with my schoolwork	○	○	○	○	○
4. I miss school because of not feeling well	○	○	○	○	○
5. I miss school to go to the doctor or hospital	○	○	○	○	○

FOR PATIENTS CURRENTLY ON SUMMER BREAK AND FOR RECENT GRADUATES: If you have been out of school for the last month, please answer the above items based on how you imagine your functioning if you were currently in school.

Appendix B

CODING MANUAL

Adherence Behaviors in Youth Following the Completion of an Intensive Interdisciplinary Pain Rehabilitation Program

This document instructs coders on how to code adherence behaviors (1) based on treatment recommendation type and (2) by follow-up appointment. Any information in italics is how a coded item is labeled in the excel coding sheet where all data will be initially entered.

The Coding Manual is divided into four sections:

1. Treatment Recommendations
2. Adherence Coding at One-Month Follow-Up
3. Adherence Coding at Six-Month Follow-Up
4. Adherence Coding at 12-Month Follow-Up

Section 1: Treatment Recommendations

Exercise (Physical Therapy Component)

Treatment Recommendation: 45 minutes of exercise every day

- This can include sports participation (if the patient was not previously participating in sports)
- Can be a combination of activities (lower body work, upper body work, core work)
- This recommendation should not be discontinued but the frequency can be adjusted if patient is no longer experiencing pain
    - Adjusted frequency: 4 days/week of 45 minutes of exercise

Desensitization (Occupational Therapy Component)

Treatment Recommendation: 5 times/day for 5-10 minutes

- This can include exercises such as rubbing, massaging, cold, and heat to the affected/painful area
- This recommendation can be discontinued if patient is no longer experiencing allodynia (pain to the touch)

Counseling (Psychological Component)

Treatment Recommendation: Participation in biweekly counseling, for at least 4 months

- There are no specifications regarding the time of counseling or the type of provider
- This recommendation may discontinue after the 4 months have been met; however, many patients often continue with this treatment

Self-Regulation (Psychological Component)

Treatment Recommendation: Self-Regulation exercises 2-3 times/day

- Self-regulation activities mat include deep breathing, guided imagery, progressive muscle relaxation, yoga, and mindfulness exercises
- This recommendation is not one that should be discontinued or adjusted

Section 2: Adherence Coding at One-Month Follow-Up

1. Exercise at One-Month Follow-Up (*EX1*)

    - 2 – Full Adherence
        - Code as full adherence if patient is completing exercise recommendation at 80% or above
        - 80% cut-off = 5 days of 45 minutes at minimum; 6 days at 40 minutes/day, 7 days at 35 minutes/day
        - Participation in sports counts as exercise if that participation was not occurring before RAPS participation
        - NOTE: If patient is not experiencing any pain, exercise needs to be occurring at least 4 days for 45 minutes

    - 1 – Partial Adherence
        - Any level of exercise that is below the above described 80% cut-off and more than once week on average

    - 0 – Not Adherent
        - Participation is not occurring at all
        - Participation in exercise is occurring at less than an average of one time per week

2. Desensitization at One-Month Follow-Up (*DES1*)

    - 2 – Full Adherence
        - Code as full adherence if patient is completing desensitization recommendation at 80% or above
        - 80% cut-off = 4 times or more a day (at least 5 minutes)
        - NOTE: If patient is not experiencing allodynia, then desensitization can be discontinued and code as full adherence

    - 1 – Partial Adherence
        - Any level of desensitization that is below the above described 80% cut-off and more than once a day on average

    - 0 – Not Adherent
        - Participation is not occurring at all
        - Participation in desensitization averages less than once a day

3. Counseling at One-Month Follow-Up (*CO1*)

    - 2 – Full Adherence
        - Participation in biweekly counseling

- 1 – Partial Adherence
  - If patient is on a waitlist or seeking out treatment
  - If patient is in treatment less than biweekly (e.g., once a month)

- 0 – Not Adherent
  - Participation is not occurring at all or no effort to seek counseling services

4. Self-Regulation at One-Month Follow-Up (*SR1*)

   - 2 – Full Adherence
     - Code as full adherence if patient is completing self-regulation recommendation at 80% or above
     - 80% cut-off = participating in self regulation at least 2 times (4 days/week) and 1 time the remaining three days (total of 11 events)

   - 1 – Partial Adherence
     - Any level of self-regulation that is below the above described 80% cut-off and more than an average of 3 times/week

   - 0 – Not Adherent
     - Participation is not occurring at all
     - Participation in self-regulation exercises averages less than three times a week

Section 3: Adherence Coding at Six-Month Follow-Up

1. Exercise at Six-Month Follow-Up (*EX2*)

    - 2 – Full Adherence
        - Code as full adherence if patient is completing exercise recommendation at 80% or above
        - 80% cut-off = 5 days of 45 minutes at minimum; 6 days at 40 minutes/day, 7 days at 35 minutes/day
        - Participation in sports counts as exercise if that participation was not occurring before RAPS participation
        - NOTE: If patient is not experiencing any pain, exercise needs to be occurring at least 4 days for 45 minutes

    - 1 – Partial Adherence
        - Any level of exercise that is below the above described 80% cut-off and more than once week on average

    - 0 – Not Adherent
        - Participation is not occurring at all
        - Participation in exercise is occurring at less than an average of one time per week

2. Desensitization at Six-Month Follow-Up (*DES2*)

    - 2 – Full Adherence
        - Code as full adherence if patient is completing desensitization recommendation at 80% or above
        - 80% cut-off = 4 times or more a day (at least 5 minutes)
        - NOTE: If patient is not experiencing allodynia, then desensitization can be discontinued and code as full adherence

    - 1 – Partial Adherence
        - Any level of desensitization that is below the above described 80% cut-off and more than once a day on average

    - 0 – Not Adherent
        i. Participation is not occurring at all
        ii. Participation in desensitization averages less than once a day

3. Counseling at Six-Month Follow-Up (*CO2*)

    - 2 – Full Adherence
        - Participation in biweekly counseling

        - NOTE: If patient completed at least 4 months of biweekly counseling at this point and has discontinued those services then code as adherent

    - 1 – Partial Adherence
        - If patient is on a waitlist or seeking out treatment
        - If patient is in treatment less than biweekly (e.g., once a month)

    - 0 – Not Adherent
        i. Participation is not occurring at all or no effort to seek counseling services

4. Self-Regulation at Six-Month Follow-Up (*SR2*)

    - 2 – Full Adherence
        - Code as full adherence if patient is completing self-regulation recommendation at 80% or above
        - 80% cut-off = participating in self regulation at least 2 times (4 days/week) and 1 time the remaining three days (total of 11 events)

    - 1 – Partial Adherence
        - Any level of self-regulation that is below the above described 80% cut-off and more than an average of 3 times/week

    - 0 – Not Adherent
        i. Participation is not occurring at all
        ii. Participation in self-regulation exercises averages less than three times a week

Section 4: Adherence Coding at 12-Month Follow-Up

1.Exercise at 12-Month Follow-Up (*EX3*)

- 2 – Full Adherence
  - Code as full adherence if patient is completing exercise recommendation at 80% or above
  - 80% cut-off = 5 days of 45 minutes at minimum; 6 days at 40 minutes/day, 7 days at 35 minutes/day
  - Participation in sports counts as exercise if that participation was not occurring before RAPS participation
  - NOTE: If patient is not experiencing any pain, exercise needs to be occurring at least 4 days for 45 minutes

- 1 – Partial Adherence
  - Any level of exercise that is below the above described 80% cut-off and more than once week on average

- 0 – Not Adherent
  i. Participation is not occurring at all

2. Desensitization at 12-Month Follow-Up (*DES3*)

- 2 – Full Adherence
  - Code as full adherence if patient is completing desensitization recommendation at 80% or above
  - 80% cut-off = 4 times or more a day (at least 5 minutes)
  - NOTE: If patient is not experiencing allodynia, then desensitization can be discontinued and code as full adherence

- 1 – Partial Adherence
  - Any level of desensitization that is below the above described 80% cut-off and more than once a day on average

- 0 – Not Adherent
  - Participation is not occurring at all
  - Participation in desensitization averages less than once a day

3. Counseling at 12-Month Follow-Up (*CO3*)

- 2 – Full Adherence
  - Participation in biweekly counseling

        - NOTE: If patient completed at least 4 months of biweekly counseling at this point and has discontinued those services then code as adherent

    - 1 – Partial Adherence
        - If patient is on a waitlist or seeking out treatment
        - If patient is in treatment less than biweekly (e.g., once a month)

    - 0 – Not Adherent
        - Participation is not occurring at all or no effort to seek counseling services

4. Self-Regulation at 12-Month Follow-Up (*SR3*)
    - 2 – Full Adherence
        - Code as full adherence if patient is completing self-regulation recommendation at 80% or above
        - 80% cut-off = participating in self regulation at least 2 times (4 days/week) and 1 time the remaining three days (total of 11 events)

    - 1 – Partial Adherence
        - Any level of self-regulation that is below the above described 80% cut-off and more than an average of 3 times/week

    - 0 – Not Adherent
        - Participation is not occurring at all
        - Participation in self-regulation exercises averages less than three times a week